Brief Comprehensive Quality of Life Assessment After Stroke
The Assessment of Quality of Life Instrument in the North East Melbourne Stroke Incidence Study (NEMESIS)

Jonathan W. Sturm, MBChB; Richard H. Osborne, PhD; Helen M. Dewey, PhD; Geoffrey A. Donnan, MD; Richard A.L. Macdonell, MD; Amanda G. Thrift, PhD

Background and Purpose—Generic utility health-related quality of life instruments are useful in assessing stroke outcome because they facilitate a broader description of the disease and outcomes, allow comparisons between diseases, and can be used in cost-benefit analysis. The aim of this study was to validate the Assessment of Quality of Life (AQoL) instrument in a stroke population.

Methods—Ninety-three patients recruited from the community-based North East Melbourne Stroke Incidence Study between July 13, 1996, and April 30, 1997, were interviewed 3 months after stroke. Validity of the AQoL was assessed by examining associations between the AQoL and comparator instruments: the Medical Outcomes Short-Form Health Survey (SF-36); London Handicap Scale; Barthel Index; National Institutes of Health Stroke Scale; and Irritability, Depression, Anxiety scale. Sensitivity of the AQoL was assessed by comparing AQoL scores from groups of patients categorized by severity of impairment and disability and with total anterior circulation syndrome (TACS) versus non-TACS. Predictive validity was assessed by examining the association between 3-month AQoL scores and outcomes of death or institutionalization 12 months after stroke.

Results—Overall AQoL utility scores and individual dimension scores were most highly correlated with relevant scales on the comparator instruments. AQoL scores clearly differentiated between patients in categories of severity of impairment and disability and between patients with TACS and non-TACS. AQoL scores at 3 months after stroke predicted death and institutionalization at 12 months.

Conclusions—The AQoL demonstrated strong psychometric properties and appears to be a valid and sensitive measure of health-related QoL after stroke. (Stroke. 2002;33:2888-2894.)

Key Words: cerebrovascular disorders | health status | outcome assessment | quality of life

Health-related quality of life (HRQoL) is an important index of outcome after stroke and is likely to be more relevant to the patient than impairment or disability. Measurement of HRQoL may be useful in natural history studies, in assessing the effectiveness of acute interventions, and in the evaluation of rehabilitation and community support programs. From a societal perspective, it is also important to measure the efficiency of interventions, including health gains per monetary value expended. Although there is debate about the relative merits of generic versus stroke-specific HRQoL measures,2,3 generic utility HRQoL instruments can directly measure health status, allow comparison across diseases, and facilitate economic evaluation.

The Assessment of Quality of Life (AQoL) instrument4,5 was designed (1) to ensure coverage of the full universe of HRQoL, (2) to meet standard psychometric requirements for reliable and valid measurement, (3) to be sensitive to a wide range of health states from very good to extremely poor health, and (4) to deliver psychometrically sound scores on the different dimensions of HRQoL. The AQoL has been successfully used in nonstroke populations.6–10 Other generic instruments have been used to collect HRQoL data in stroke survivors. These include the Medical Outcomes Short-Form Health Survey (SF-36),11 and the Euroqol.12 Both have been criticized for a lack of sensitivity.2 Similar to the Euroqol, the AQoL yields both a descriptive profile and a single value that quantifies overall HRQoL. The Euroqol is simple and slightly quicker to complete than the AQoL, but appears to have poorer coverage of stroke-relevant HRQoL. The SF-36 takes longer to complete than the AQoL. Scores are provided from 8 subscales (or 2 summary subscales). The use of multiple subscales may be viewed as advantageous because of the diversity in the recovery process from stroke; however, it may also make the interpretation of overall outcome difficult because gains in 1 domain can be offset by losses in other domains. The AQoL appears to have advantages

Received November 1, 2001; final revision received July 15, 2002; accepted July 17, 2002.
From the National Stroke Research Institute and Department of Neurology, Austin and Repatriation Medical Centre (J.W.S., H.M.D., G.A.D., R.A.L.M., A.G.T.); Centre for Health Program Evaluation, School of Population Health (R.H.O.); Department of Medicine, University of Melbourne (R.H.O., H.M.D., G.A.D., R.A.L.M., A.G.T.); and Department of Epidemiology and Preventive Medicine, Monash Medical School, Alfred Hospital (A.G.T.), Melbourne, Australia.
Correspondence to Dr Jonathan Sturm, National Stroke Research Institute, Repatriation Campus, Austin and Repatriation Medical Centre, Banksia St, West Heidelberg Vic 3081, Australia. E-mail jsturm@austin.unimelb.edu.au © 2002 American Heart Association, Inc.

Stroke is available at http://www.strokeaha.org

DOI: 10.1161/01.STR.0000040407.44712.C7
over existing generic measures of HRQoL and health status in that it offers brief assessment, better coverage of stroke-specific domains (eg, communication and vision), and 1 overall score facilitating analysis and can be used in economic analysis. However, the validity of the AQoL as a measure of HRQoL in stroke has not been established. The aim of this study was to validate the AQoL as a measure of HRQoL in a population of stroke survivors.

Methods

The North East Melbourne Stroke Incidence Study

Stroke survivors were recruited from the North East Melbourne Stroke Incidence Study (NEMESIS), a community-based study of the incidence, risk factors, and outcomes of stroke in the northeastern suburbs of Melbourne, Australia. The methods have previously been described in detail. Briefly, NEMESIS was conducted in an 8-postal code region containing a population of 313,816 in northeast Melbourne between May 1, 1996, and April 30, 1997. The methodology used to obtain stroke cases was based on the recommendations for the conduct of “ideal” stroke incidence studies. All potential cases of stroke were reviewed by a panel of at least 2 neurologists and 1 epidemiologist before inclusion in the study. Cases meeting the World Health Organization (WHO) definition of stroke were registered. Pathological evaluation before inclusion in the study. Cases meeting the World Health Organization (WHO) definition of stroke were registered. Patients who had neither neuroimaging nor autopsy were classified as undetermined. Patients were further categorized by an expert panel blinded to brain imaging findings that used the Oxfordshire Community Stroke Project stroke classification using symptoms and signs at the time of maximal deficit. Patients with SAH were included in incidence and mortality counts but were not formally followed up in NEMESIS.

Follow-Up

Patients were administered the AQoL, and comparator instruments by trained research nurses via face-to-face interview 3 months after stroke. If a patient was unable to complete the interview because of dementia or aphasia, a face-to-face proxy interview was sought from the best available informant, usually the next of kin or, if necessary, a professional caregiver.

Subjects

For the purposes of the present study, all patients who had a first-ever-in-a-lifetime or recurrent stroke (CI, ICH, or undetermined but not SAH) between July 13, 1996, and April 30, 1997, were eligible for inclusion. Two hundred sixty-one patients had a stroke (CI, ICH, or undetermined) in this period. At 3 months after stroke, 72 (28%) were deceased. Thirty-three patients (13%) were notified to the NEMESIS study >3 months after stroke, and 63 (24%) refused to take part. Therefore, 93 patients (60% of those approached, 49% of those alive at 3 months) were enrolled in the study. The mean age was 72 years (range, 28 to 89 years), 45% were male, and 70% were born in Australia; for 83%, this was a first-ever-in-a-lifetime stroke. Of the total patients, 10% had total anterior circulation infarction, 37% had partial anterior circulation infarction, 19% had posterior circulation infarction, 26% had lacunar infarction, and 6% had ICH; in 2 patients, stroke type was undetermined. Patients included in this study did not differ significantly from those who refused to take part or were notified late to the NEMESIS study in terms of age, sex, stroke subtype, or prestroke disability. Those not included were significantly more likely to have been born outside Australia (P = 0.05) and to have been admitted to a private hospital (P = 0.02).

Instruments

The AQoL instrument is a generic HRQoL utility instrument that includes 5 dimensions of HRQoL: independent living, social relationships, physical senses, psychological well-being, and illness (reproduced in full in the Appendix). Scores from the first 4 dimensions only are used to calculate an overall utility score. Each individual scale is weighted to extend between 0.0 (death) and 1.0 (full health). However, the overall utility score range is from −0.04 (worst possible HRQoL state) to 0.00 (death-equivalent HRQoL state) to 1.00 (full HRQoL). The utilities were derived using time tradeoff methodology in a sample of the general population. The AQoL was designed to be administered by self-completion, through face-to-face interview, or via proxy. It takes approximately 5 minutes to complete and has been well validated in the general population.

The SF-36 (1) is a widely used and validated generic HRQoL instrument. It comprises 8 subscales: physical functioning, role physical, bodily pain, general health, vitality, social function, role emotional, and mental health. Each of the subscales is scored separately using item weighting and additive scaling. Summed data are transformed onto a 0-to-100-point scale. The 8 subscales can be combined into 2 summary health status measures, physical function and mental health. The acute (1-week time frame) version of the SF-36 was used. Impairment was measured with the National Institutes of Health Stroke Scale (NIHSS) (range, 0 to 42). Patients were categorized into prespecified groups by severity of impairment with 5-point intervals. Categorization into 5-point intervals has been used in previous studies and represents a clinically relevant score threshold. Because of the small number of patients with very high impairment scores in our sample, we collapsed the patients scoring >10 into 1 category, ie, 0 to 5, 6 to 10, and >10.

Disability was assessed with the Barthel Index. Patients were scored according to current actual performance of activities of daily living. Severity of disability was determined by stratifying patients into prespecified categories: very severely (Barthel 0 to 4), severely (5 to 9), moderately (10 to 14), or mildly (15 to 19) disabled or nondisabled (20 of 20).

Handicap was assessed with the London Handicap Scale (LHS). This provides a descriptive profile of disadvantages experienced in the domains of mobility, physical independence, occupation, orientation, social functioning, and economic self-sufficiency. A weighted total handicap score is produced, with scores ranging from 0 (maximum disadvantage) to 100 (no disadvantage).

For the purposes of this study, only the two 5-question subscales pertaining to depression and anxiety were used. For each of these subscales, a score ranging from 0 to 15 is produced, with higher scores reflecting greater mood impairment.

These questionnaires were chosen to enable comparison between AQoL scores and scores from established instruments that measure different levels of outcome according to the WHO International Classification of Impairments, Disabilities, and Handicaps (ICIDH).

Statistical Analysis

The construct validity of the AQoL was assessed by examining the relationships between the AQoL (individual dimensions and total utility score) and the NIHSS, Barthel Index, LHS, SF-36 subscales, and the depression and anxiety subscales of the IDA at 3 months after stroke using Spearman’s rank correlation coefficient (R). For a sample size of 93 and the null hypothesis R = 0, the critical values are P = 0.05, R = 0.204; P = 0.01, R = 0.267; and P = 0.001, R = 0.338. We hypothesized that the magnitude of correlation would be highest between scales measuring similar constructs (providing evidence of convergent validity) and the weakest correlations would be between scales measuring conceptually unrelated constructs (discriminant validity). For example, we expected that the independent living dimension of the AQoL would be more highly correlated with the Barthel Index than with measures of mental health and, conversely, the psychological well-being dimension to be more highly correlated with the IDA subscales than with the Barthel Index.

Criterion validity is assessed by comparing a measure with a gold standard. Because there is no gold standard for HRQoL, we compared the AQoL with instruments that measure different levels of outcome according to the WHO ICIDH. The AQoL was constructed with a primary emphasis on handicap but with supplementation from the concepts of impairment and disability. Given
the framework for the construction of the AQoL, we hypothesized that the overall AQoL utility scores would be more strongly correlated with the LHS (handicap) than with the Barthel Index (disability) or NIHSS (impairment).

To assess the sensitivity of the AQoL (and to provide further evidence of construct validity), we performed a series of known-groups validations. We compared mean AQoL utility scores (using 1-way analysis of variance [ANOVA]) between groups of patients categorized by severity of disability and severity of impairment, hypothesising that AQoL scores would be lower (worse HRQoL) in those patients with greater disability and impairment. The sensitivity of the AQoL was compared with the NIHSS, Barthel Index, LHS, SF-36, and depression and anxiety subscales of the IDA by examining scores obtained from patients with total anterior circulation syndrome (TACS) stroke and patients with non-TACS stroke. Relative efficiencies (RE), the ratio of the squares of the t statistic, were calculated for each instrument and compared with the RE of the AQoL.

TABLE 1. Association Between the AQoL and Other Health Status Measures in Patients 3 Months After Stroke (Spearman’s rank correlation)

<table>
<thead>
<tr>
<th>Dimensions of the AQoL</th>
<th>Illness*</th>
<th>Independent Living</th>
<th>Social Relationships</th>
<th>Physical Senses</th>
<th>Psychological Wellbeing</th>
<th>AQoL Total Score*</th>
</tr>
</thead>
<tbody>
<tr>
<td>SF-36</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical functioning</td>
<td>0.30†</td>
<td>0.77§</td>
<td>0.37§</td>
<td>0.28†</td>
<td>0.26†</td>
<td>0.69§</td>
</tr>
<tr>
<td>Role physical</td>
<td>0.24†</td>
<td>0.20</td>
<td>0.26†</td>
<td>0.19</td>
<td>0.19</td>
<td>0.27§</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>0.21†</td>
<td>0.06</td>
<td>0.16</td>
<td>0.04</td>
<td>0.01§</td>
<td>0.20</td>
</tr>
<tr>
<td>General health</td>
<td>0.31†</td>
<td>0.27†</td>
<td>0.25†</td>
<td>0.21†</td>
<td>0.39§</td>
<td>0.36§</td>
</tr>
<tr>
<td>Vitality</td>
<td>0.17</td>
<td>0.39§</td>
<td>0.41§</td>
<td>0.26†</td>
<td>0.37§</td>
<td>0.47§</td>
</tr>
<tr>
<td>Social functioning</td>
<td>0.20</td>
<td>0.44§</td>
<td>0.48§</td>
<td>0.31†</td>
<td>0.36§</td>
<td>0.54§</td>
</tr>
<tr>
<td>Role emotional</td>
<td>0.09</td>
<td>0.00</td>
<td>0.21†</td>
<td>0.37§</td>
<td>0.18</td>
<td>0.15</td>
</tr>
<tr>
<td>Mental health</td>
<td>0.04</td>
<td>0.40§</td>
<td>0.50§</td>
<td>0.31†</td>
<td>0.41§</td>
<td>0.51§</td>
</tr>
<tr>
<td>Physical summary</td>
<td>0.35§</td>
<td>0.44§</td>
<td>0.22†</td>
<td>0.07</td>
<td>0.38§</td>
<td>0.44§</td>
</tr>
<tr>
<td>Mental summary</td>
<td>0.06</td>
<td>0.19</td>
<td>0.44§</td>
<td>0.39§</td>
<td>0.32†</td>
<td>0.36§</td>
</tr>
<tr>
<td>London Handicap Scale</td>
<td>0.30†</td>
<td>0.62§</td>
<td>0.56§</td>
<td>0.52§</td>
<td>0.52§</td>
<td>0.83§</td>
</tr>
<tr>
<td>Barthel Index (disability)</td>
<td>0.25†</td>
<td>0.85§</td>
<td>0.44§</td>
<td>0.45§</td>
<td>0.16</td>
<td>0.77§</td>
</tr>
<tr>
<td>NIHSS (impairment)</td>
<td>-0.06</td>
<td>-0.74§</td>
<td>-0.39§</td>
<td>-0.40§</td>
<td>-0.12</td>
<td>-0.69§</td>
</tr>
<tr>
<td>Anxiety</td>
<td>-0.15</td>
<td>-0.51§</td>
<td>-0.49§</td>
<td>-0.31†</td>
<td>-0.47§</td>
<td>-0.60§</td>
</tr>
<tr>
<td>Depression</td>
<td>-0.15</td>
<td>-0.41§</td>
<td>-0.44§</td>
<td>-0.12</td>
<td>-0.53§</td>
<td>-0.53§</td>
</tr>
</tbody>
</table>

*Scores from the Illness dimension are not included in the calculation of the AQoL utility score.
†P<0.05, ‡P<0.01, §P<0.001 for the hypothesis R=0.28

Results

All 93 patients completed the AQoL. Fifteen subjects (16%) were assessed by means of a proxy response. The mean AQoL utility score was 0.404, the median was 0.365, and the SD was 0.333. The data were not significantly skewed, and scores were distributed evenly throughout the available range. Two patients (2%) scored −0.04 (lowest possible score), and only 1 patient (1%) scored 1.0 (highest possible score), demonstrating no substantial floor or ceiling effects. Ninety-two patients were assessed with the Barthel Index, LHS, and SF-36; 88 were assessed with the NIHSS; and 79 were assessed with the IDA.
The association between the AQoL and its individual dimensions and the other instruments is shown in Table 1. The magnitude of the correlations was greatest between scales with the most similar construct. The independent living dimension of the AQoL correlated most strongly with the Barthel Index (R = 0.85), followed by the LHS (R = 0.82), NIHSS (R = -0.74), and SF-36 physical functioning subscale (R = 0.77). The social relationships dimension was most highly correlated with the LHS (R = 0.56), anxiety (R = -0.49), and SF-36 social functioning (R = 0.48) and mental health (R = 0.50) subscales. The physical senses dimension correlated most strongly with the LHS (R = 0.52), Barthel Index (R = 0.45), and NIHSS (R = -0.40). The highest correlations for the psychological well-being dimension were with the depression (R = -0.53) and anxiety (R = -0.47) subscales and the SF-36 bodily pain (R = 0.61) and mental health (R = 0.41) subscales. The total AQoL score was most highly associated with the LHS (R = 0.83) and Barthel Index (R = 0.77).

The relationships between mean AQoL score and categories of disability (Figure 1) and impairment were in the expected direction. Highest HRQoL was observed when disability and impairment were least. The differences in total AQoL scores across categories of disability and impairment were significant (P < 0.001, ANOVA).

The total AQoL and independent living dimension, SF-36 physical function subscale, LHS, Barthel Index, and NIHSS discriminated significantly between the health status of TACS and non-TACS patients in both parametric (t-test) and nonparametric (permutations tests33) analyses (Table 2).

The AQoL utility score (RE referenced to 1.0) discriminated between TACS and non-TACS patients more efficiently than the SF-36 (RE, 0.01 to 0.54), LHS (RE, 0.45), Barthel Index (RE, 0.50), IDA (RE, 0.02 to 0.10), and NIHSS (RE, 0.47). Only the independent living subscale of the AQoL discriminated between these groups of patients with more efficiency than the total AQoL score (RE, 1.84).

In logistic regression models, the AQoL 3-month score was a significant predictor of the outcomes of death (13 cases), institutionalization (7 cases), or both 12 months after stroke. The follow-

<table>
<thead>
<tr>
<th>TABLE 2. Ability of Instruments to Discriminate Between Patients With Total Anterior Circulation Syndrome (TACS) and Non-TACS at 3 Months After Stroke (n = 87*)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean Score</strong></td>
</tr>
<tr>
<td><strong>AQoL</strong></td>
</tr>
<tr>
<td>Total (utility score)</td>
</tr>
<tr>
<td>Illness</td>
</tr>
<tr>
<td>Independent living</td>
</tr>
<tr>
<td>Social relationships</td>
</tr>
<tr>
<td>Physical senses</td>
</tr>
<tr>
<td>Psychological wellbeing</td>
</tr>
<tr>
<td><strong>SF-36</strong></td>
</tr>
<tr>
<td>Physical function</td>
</tr>
<tr>
<td>Role physical</td>
</tr>
<tr>
<td>Bodily pain</td>
</tr>
<tr>
<td>General health</td>
</tr>
<tr>
<td>Vitality</td>
</tr>
<tr>
<td>Social function</td>
</tr>
<tr>
<td>Role emotional</td>
</tr>
<tr>
<td>Mental health</td>
</tr>
<tr>
<td>Physical summary</td>
</tr>
<tr>
<td>Mental summary</td>
</tr>
<tr>
<td>London Handicap Scale</td>
</tr>
<tr>
<td>Barthel Index (disability)</td>
</tr>
<tr>
<td>Irritability Depression Anxiety scale</td>
</tr>
<tr>
<td>Anxiety</td>
</tr>
<tr>
<td>Depression</td>
</tr>
<tr>
<td>NIHSS (impairment)</td>
</tr>
</tbody>
</table>

RE indicates relative efficiency, the ratio of the squares of the t statistic. REs of each scale are shown relative to the RE of the total AQoL; ie, any scale with RE > 1.0 is more efficient, and <1.0 less, in discriminating between groups.

*Six patients with definite intracerebral hemorrhage were excluded from this analysis.
†Student’s unpaired t test (2-sided). Differences between groups significant on t tests were also significant using nonparametric methods (permutations tests33).
The AUC for the model predicting death or institutionalization was 0.773 (SE, 0.056; \( P < 0.001 \) for the null hypothesis that \( \text{AUC} = 0.5 \)). For institutionalization alone, \( \text{AUC} = 0.829, \text{SE} = 0.05, \) and \( P = 0.004 \). For death alone, \( \text{AUC} = 0.692, \text{SE} = 0.074, \) and \( P = 0.027 \).

When adjusted for age, sex, and 3-month impairment score, AQoL score at 3 months remained a significant predictor of death or institutionalization (\( P = 0.006 \)). Actual and predicted rates of death or institutionalization at 12 months after stroke according to AQoL utility score at 3 months are shown in Figure 2.

**Discussion**

We have provided evidence that the AQoL is a valid instrument for assessing HRQoL after stroke. The strongest associations of AQoL and its dimensions with other measures were observed between scales measuring similar constructs, and the weakest relationships were between conceptually unrelated scales, indicating convergent and discriminant validity. The independent living dimension, as expected, correlated best with measures of physical impairment, disability, handicap, and physical functioning. The social relationships dimension correlated most highly with measures of disability, social functioning, and mood impairment, suggesting that both physical and psychological functioning is important for satisfying relationships. The physical senses dimension correlated best with disability and handicap measures. Low correlations between this dimension and SF-36 scales are expected because the items covered (seeing, hearing, communication) are not specifically addressed by the SF-36. The psychological well-being dimension was correlated most highly with other measures of psychological function. The psychological well-being incorporates pain assessment, which explains the high correlation with the SF-36 bodily pain scale.

Total AQoL utility scores were more strongly correlated with scores from the LHS (handicap) than with the Barthel Index (disability) and NIHSS (impairment), and this, together with the moderate correlation between the AQoL and most SF-36 subscales, suggests strong criterion validity. The highest correlation was with the LHS, which was expected because the design of the AQoL included a substantial emphasis on handicap and because the LHS is also a utility instrument that incorporates community preferences of the patients’ health status. There are major differences between the AQoL and the SF-36, so high correlations between these instruments should not be expected. The AQoL is a multiattribute utility instrument designed to measure HRQoL. Although a description of the patient’s difficulties relating to health is provided, these levels of health are then substituted during scoring by population preference weights established through the time tradeoff procedure whereby respondents “trade off” life length for health level. The AQoL utility value is presented, therefore, on a life-death scale in which the lower boundary is −0.04 (HRQoL states valued worse than death), 0.00 (HRQoL states valued equivalently to death), to 1.0 (HRQoL states valued as perfect HRQoL). The appropriateness of a possible “worse than death” utility for major stroke has been previously discussed. The SF-36 is used to describe the patient’s health status largely in terms of the impact of health on activities, although perception of general health status and mood are also assessed. Dimension scores for the SF-36 are computed with a non–preference-weighted additive model in which the scores representing health status are quantified on a 0-to-100-point rating scale. Given these differences between instruments, the correlations are of the magnitude expected.

The AQoL was sensitive in discriminating differences in health status between patients with varying severity of stroke, as defined by disability and impairment scores. The utilities observed for severe and mild stroke are similar to those reported elsewhere. Through the use of the RE, it was observed that the AQoL was more efficient than the SF-36, LHS, Barthel Index, NIHSS, and the anxiety and depression subscales of the IDA in discriminating between the health status of TACS and non-TACS patients. It is possible that some severe cases of stroke may have been included in the non-TACS group (eg, some posterior circulation strokes may be severe); however, this would tend to minimize differences, and the AQoL was able to clearly differentiate between these groups. No substantial ceiling or floor effects were observed for the overall utility score. Finally, AQoL scores at 3 months after stroke predicted future death or institutionalization, demonstrating the predictive validity of the instrument.

The lack of consistency between studies in the choice of outcome measure makes interpretation and comparison between studies difficult. The use of a single measure in place of multiple scales would be less burdensome on patients and would simplify the interpretation of results. The concordance between data obtained from the AQoL and those obtained from measures of physical and mood impairment, disability, and handicap, coupled with the demonstrated sensitivity in discriminating between different health states, suggests that further study is warranted to assess whether the AQoL could potentially be used as a sole outcome measure in trials or natural history studies.

The illness domain was included in the original development of the AQoL scale, but this scale is not used to derive an overall utility score. For those researchers who wish to have the most parsimonious questionnaire, the 3 questions related to the Illness scale could be omitted, resulting in a brief 12-item instrument. Although not designed specifically for stroke patients and having no specific questions about upper-
extremity function and cognition, as included in stroke-specific HRQoL instruments, the AQoL performs well. Despite its brevity, it captures much of the variance of the handicap, disability, and impairment instruments and returns information on broader aspects of HRQoL. The performance of the AQoL is most likely due to the relevance of its domains to stroke survivors (self-care, household tasks, mobility, relationships, social isolation, family role, seeing, hearing, communication, sleep, anxiety and depression, and pain). The questionnaire is easy to use, taking 5 minutes to administer to most patients. It can be used in a variety of settings because it was designed for self-completion or use at interview, and it appears suitable for proxy assessments.

Recently, a stroke-specific QOL scale (12 domains, 78 items) and a stroke impact scale (8 domains, 64 items) have been developed. These have the advantage of returning substantial detail on stroke-specific outcomes, but their length, lack of a single outcome score, and inability to be used in nonstroke comparison groups may make them unsuitable for use in some studies. Further validation of the AQoL using stroke-specific HRQoL scales would be useful.

The AQoL can be recommended for use in cross-sectional studies of outcome after stroke. Further evaluation is required to replicate these findings in other stroke populations, to confirm its usefulness in longitudinal studies, and to formally examine the reliability of proxy assessment. Despite these caveats, we have provided initial evidence that the AQoL is a valid, sensitive measure of HRQoL in stroke patients.

Acknowledgments

This work was supported by grants from the Public Health Research and Development Committee of the National Health & Medical Research Council, the Victorian Health Promotion Foundation, Foundation for High Blood Pressure Research, and the National Stroke Foundation. Dr. Sturm was supported by a postgraduate medical scholarship provided by the National Health & Medical Research Council. Lichun Quang provided assistance with database management and analysis. Donna Bradford and Lucie O’Malley provided administrative support. The contribution of the following research nurses is also gratefully acknowledged: Stephen Cross, Barbara Dowell, Elsaeth Freeman, Jodi Haartsen, Meg Hooton, Amanda Loth, Sally Roberts, Catherine Sharples, Mary Stiaos, Cathy Taranto and Dennis Young. We thank Dr. John Ludbrook (Biomedical Statistical Consulting Service) for assistance with the statistical analyses.

References

Appendix

THE Australian Quality of Life (AQoL) INSTRUMENT

INSTRUCTIONS:
Please tick the alternative that best describes you during the last week.

ILLNESS
1. Concerning my use of prescribed medicines:
   - I do not or rarely use any medicines at all. ☐
   - I use one or two medicinal drugs regularly. ☐
   - I need to use three or four medicinal drugs regularly. ☐
   - I use five or more medicinal drugs regularly. ☐

2. To what extent do I rely on medicines or a medical aid? (NOT glasses or a hearing aid.) (For example: walking frame, wheelchair, prosthesis etc.)
   - I do not use any medicines and/or medical aids. ☐
   - I occasionally use medicines and/or medical aids. ☐
   - I regularly use medicines and/or medical aids. ☐
   - I have to constantly take medicines or use a medical aid. ☐

3. Do I need regular medical treatment from a doctor or other health professional?
   - I do not need regular medical treatment. ☐
   - Although I have some regular medical treatment, I am not dependent on this. ☐
   - I am dependent on having regular medical treatment. ☐
   - My life is dependent upon regular medical treatment. ☐

INDEPENDENT LIVING
4. Do I need any help looking after myself?
   - I need no help at all. ☐
   - Occasionally I need some help with personal care tasks. ☐
   - I need help with the more difficult personal care tasks. ☐
   - I need daily help with most or all personal care tasks. ☐

5. When doing household tasks: (For example: preparing food, gardening, using the video recorder, radio, telephone or washing the car)
   - I need no help at all. ☐
   - Occasionally I need some help with household tasks. ☐
   - I need help with the more difficult household tasks. ☐
   - I need daily help with most or all household tasks. ☐

6. Thinking about how easily I can get around my home and community:
   - I get around my home and community by myself without any difficulty. ☐
   - I find it difficult to get around my home and community by myself. ☐
   - I cannot get around the community by myself, but I can get around my home with some difficulty. ☐
   - I cannot get around either the community or my home by myself. ☐

SOCIAL RELATIONSHIPS
7. Because of my health, my relationships (For example: with my friends, partner or parents) generally:
   - Are very close and warm. ☐
   - Are sometimes close and warm. ☐
   - Are seldom close and warm. ☐
   - I have no close and warm relationships. ☐

8. Thinking about my relationship with other people:
   - I have plenty of friends, and am never lonely. ☐
   - Although I have friends, I am occasionally lonely. ☐
   - I have some friends, but am often lonely for company. ☐
   - I am socially isolated and feel lonely. ☐

Appendix (continued)

9. Thinking about my health and my relationship with my family:
   - My role in the family is unaffected by my health. ☐
   - There are some parts of my family role I cannot carry out. ☐
   - There are many parts of my family role I cannot carry out. ☐
   - I cannot carry out any part of my family role. ☐

PHYSICAL SENSES
10. Thinking about my vision, including when using my glasses or contact lenses if needed:
    - I see normally. ☐
    - I have some difficulty focusing on things, or I do not see them sharply. ☐
    - For example: small print, a newspaper, or seeing objects in the distance. ☐
    - I have a lot of difficulty seeing things. My vision is blurred. ☐
    - For example: I can see just enough to get by with. ☐
    - I only see general shapes, or am blind. ☐
    - For example: I need a guide to move around. ☐

11. Thinking about my hearing, including using my hearing aid if needed:
    - I hear normally. ☐
    - I have some difficulty hearing or I do not hear clearly. ☐
    - For example: I ask people to speak up, or turn up the TV or radio volume. ☐
    - I have difficulty hearing things clearly. ☐
    - For example: Often I do not understand what is said. I usually do not take part in conversations because I cannot hear what is said. ☐
    - I hear very little indeed. ☐
    - For example: I cannot fully understand loud voices speaking directly to me. ☐

12. When I communicate with others: (For example: by talking, listening, writing or signing)
    - I have no trouble speaking to them or understanding what they are saying. ☐
    - I have some difficulty being understood by people who do not know me. ☐
    - I have no trouble understanding what others are saying to me. ☐
    - I am only understood by people who know me well. ☐
    - I have great trouble understanding what others are saying to me. ☐
    - I cannot adequately communicate with others. ☐

PSYCHOLOGICAL WELL-BEING
13. If I think about how I sleep:
    - I am able to sleep without difficulty most of the time. ☐
    - My sleep is interrupted some of the time, but I am usually able to go back to sleep without difficulty. ☐
    - My sleep is interrupted most nights, but I am usually able to go back to sleep without difficulty. ☐
    - I sleep in short bursts only. I am awake most of the night. ☐

14. Thinking about how I generally feel:
    - I do not feel anxious, worried or depressed. ☐
    - I am slightly anxious, worried or depressed. ☐
    - I feel moderately anxious, worried or depressed. ☐
    - I am extremely anxious, worried or depressed. ☐

15. How much pain or discomfort do I experience?
    - None at all. ☐
    - I have moderate pain. ☐
    - I suffer from severe pain. ☐
    - I suffer unbearable pain. ☐
Brief Comprehensive Quality of Life Assessment After Stroke: The Assessment of Quality of Life Instrument in the North East Melbourne Stroke Incidence Study (NEMESIS)


Stroke. 2002;33:2888-2894; originally published online November 14, 2002;
doi: 10.1161/01.STR.0000040407.44712.C7

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://stroke.ahajournals.org/content/33/12/2888

Permissions: Requests for permissions to reproduce figures, tables, or portions of articles originally published in Stroke can be obtained via RightsLink, a service of the Copyright Clearance Center, not the Editorial Office. Once the online version of the published article for which permission is being requested is located, click Request Permissions in the middle column of the Web page under Services. Further information about this process is available in the Permissions and Rights Question and Answer document.

Reprints: Information about reprints can be found online at:
http://www.lww.com/reprints

Subscriptions: Information about subscribing to Stroke is online at:
http://stroke.ahajournals.org//subscriptions/